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ABSTRACT

The Center for Independent Living (CIL) in Berkeley, California, is described as a mecca for the disabled since 1972, when a coalition of severely disabled people founded the Center with the goal of integrating disabled people into the community-at-large. The CIL's mission is to create and maintain independence for disabled people through providing services, advocating for the rights of disabled individuals, and nurturing a system of support in the community. CIL is a membership organization with over 500 members who elect a governing board made up of a majority of individuals with disabilities. Services include housing, attendant referral, independent living skills training, youth services, peer counseling, job development, benefits counseling, blind services, and deaf services. Six major areas of concern to people in the developmental disability field are discussed: choices and decision making, peer support, working with attendants, disability awareness, advocacy and services, and transition and independent living. The report also discusses individual and system advocacy and acceptance of the CIL within the Berkeley community. (JDD)

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CENTER FOR INDEPENDENT LIVING (CIL): DISABLED PEOPLE TAKE THE LEAD FOR FULL COMMUNITY LIVES

Center on Human Policy

EC 301208

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CENTER FOR INDEPENDENT LIVING (CIL): DISABLED PEOPLE TAKE THE LEAD FOR FULL COMMUNITY LIVES

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This report is based on a qualitative research site visit conducted on October 19-20, 1989 with a subsequent visit on December 7, 1989. The author wishes to thank Judy Heumann, Board member, and Michael Winters, Executive Director of CIL for facilitating this visit, and Gerald Baptiste, Associate Director, for his time, insights and arrangements during the hectic days following the earthquake. Thanks also to Adina Frieden, David Lewis, Phil Chavez, Sandra Stone, Marcia Ortiz and others for sharing their insights and time during the visit; to Chris and Joel Sarch for the hospitality they extended during and subsequent to the earthquake; to Bonnie Shoultz, Susan O'Connor, Pam Walker, Rannveig Traustadottir, Sally Johnston, Judy Heumann and Steve Taylor for their comments on draft versions of this document; and to Rachael Zubal for her assistance in the preparation of this document.

It was October 19, 1989, a day and a half after a major earthquake registering 6.9 - 7.1 on the Richter scale struck the San Francisco Bay area. The news reported over 250 people killed. The majority were crushed when the top deck of Highway I-880 near Oakland collapsed on the deck below. The aftershocks, as high as 5.0, had continued through the night as the area reeled from one of the largest quakes to ever hit the Continental United States.

Driving to Berkeley via the southern route from San Jose, California, I thought about my own experiences in the earthquake. I was grateful my last minute change of plans kept me in a residential area suffering little major damage. The quake had shaken the house back and forth, starting from the top and moving downward. After a brief period of panic, I avoided a swinging chandelier as I finally unlocked an oscillating door that refused to open. I joined other Californians who gathered outdoors that day in a mixture of fear and acceptance, despite the fact that "all good Californians stand in door jams" during quakes!

The only damage reports I heard on the news from Berkeley were of a major fire and some damage to buildings. The traffic this day was slow, sometimes bumper to bumper at 15 miles an hour, with drivers coming to a full stop in the middle of major highways to let me merge--an exaggerated politeness, brought on I suspected from a fresh look at their own mortality. Even for the San Francisco area, where drivers stop at four way stop signs and take turns, this was quite out of the ordinary. As I drove, I wondered if ordinary citizens in Berkeley responded as they did in Oakland and San Francisco, by directing traffic and bringing ladders and blankets to help the people from the collapsed bridge.

I arrived in Berkeley and watched the houses, including the mixture of pastels--yellow, blue, purple, peach, light green--of the colors that dot San Francisco mingle with the deeper dark green and brown earthtones more reminiscent of the east. Bright flowers, sparkles of purple, flowed out of some yards, though much of the land was the parched color of Idaho deserts thirsting for rain.

Reaching the commercial district, I found the simple storefront sign of the independent living center. The stone clock tower of the Berkeley campus was visible down the street with the center itself sandwiched in between stores, delis, and gas stations. When I entered, I relearned what a friend shared with me yesterday, that the director of the independent living center was still in Washington working on the passage of the Americans with Disabilities Act, which was in trouble in committee.[1]

Sitting in the waiting room, I listened to a woman chat with the receptionist about the earthquake. While touching one of the wheels on her wheelchair, she shared with gentle laughter, "I was so nervous I ran over my attendant's feet two times. Hard." The Caucasian[2] receptionist, visibly touched by a story she just heard, recounted how one man survived in his crushed car on the collapsed bridge. With clear admiration for his inner strength, she looked inward and said, "I couldn't do it." I then heard the soft voice of an African-American woman next to me who said, "You'd find a way. All the stuff you've been through in your life. You'd find a way." The receptionist nodded in

[1]The Americans with Disabilities Act has since been passed by Congress and signed into law.

[2]Language to identify racial ethnicity is used here to indicate the diversity of people involved in this exchange.

quiet agreement. Another young man, Hispanic American, added his experiences, "The good part was getting phone calls from my friends. It was my first earthquake. I never experienced one here."

What is the Center for Independent Living?

The Center for Independent Living (CIL), the "first organization of its type in the world," is a visible symbol of the independent living movement, the international civil rights movement of disabled[3] people. Since 1972, when a coalition of severely disabled people founded the Center, CIL has become a mecca for the disabled, and is "now recognized worldwide as the inspiration and archetype for over 300 independent living centers" (CIL, 1989).

Following the civil rights and women's movement, disabled people took the lead to create conditions where they would be free to live their own lives and participate fully in the community. Called the independent living movement, people with all kinds of disabilities came together to work for supportive services and the federal, state, and local governmental changes necessary for full community participation. Emerging from the Physically Disabled Students' Program at the University of California-Berkeley, CIL was designed and operated by disabled people, with the goal of integrating disabled people into the community-at-large.

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[3]The author uses the political terminology of disabled people which is preferred language by people associated with this organization instead of people first language, such as people with disabilities. Use of the word disabled in this chapter stems from a form of disability pride, "disabled and proud."

CIL, and the people associated with it, have played a powerful role in the history of disability legislation in this country. As the associate director described their role in working with other groups around Section 504 of the 1973 Rehabilitation Act,

> A group of people from CIL (together with a coalition from the Bay area) took over the federal building in San Francisco...Well, everybody was saying, those disabled people, they'll be here for a couple of hours and then have to go back to the hospital...Little did they know that those disabled people were from Berkeley.
>
> They ended up staying...(over) 23 days. It was getting such hot publicity that people started coming out in droves in support. The Black Panthers were coming down bringing food everyday...all types of churches (were involved); everybody was coming in. The mayor realized they were serious. (Part of) the group...decided to trek to Washington to tell the story as it unfolded. They did a candlelight vigil. With the publicity, they finally set out (the regulations for the) law.

Within California, CIL has also played a major role in change, for example, in the area of accessible transportation, a critical issue still today nationwide. As Gerald Baptiste, the associate director, continued:

> We have pretty accessible transportation. Again, one group of disabled people decided to go to (the) San Francisco...transit terminal where the buses come over...This was peak hour when everybody was trying to get off work and get back (home). A group of disabled people went over and laid down in front of the

buses. So they (the transit authorities) realized we had better get to the negotiating table with these people. So that's how we were able to get accessible buses in this area.

The current mission of CIL, as adopted by the Board of Directors in 1987, is "...to create and maintain independence for disabled people through providing services, advocating for the rights of disabled individuals, and nurturing a system of support in the community." From its inception, CIL has maintained a focus on both supportive services and advocacy, although the balance has changed through the years. Throughout its first 16 years, CIL provided direct services to over 140,000, built 500 residential ramps free of charge for wheelchair users, helped 1,000 people secure jobs, and assisted over 600 students to complete the independent living skills training program (CIL, 1989).

Starting with a grant for $15,000, CIL reached its financial zenith in 1978 with a budget of $3.2 million and 200 employees. Partially resulting from cutbacks in funding for social efforts, as of October 1989, CIL had 51 employees and a $1.8 million budget.

How is the Center Organized?

CIL is a membership organization with over 500 members who elect the governing board. The board consists of approximately 15 people, with more than 51% mandated to be disabled people, though over 70% of the board currently represents this primary constituency. The organization's key management positions are held by disabled people who have a long-term commitment to CIL. The executive director, Michael Winters, has held that position for 7 years and the associate director, Gerald Baptiste, has been with the organization for over 11 years.

Currently the Center is organized based on a departmental model, with the service areas mentioned in Chart 1 under four "unit coordinators" in the areas of

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CHART 1
Services of the Center for Independent Living

Housing. Supports people to locate and secure accessible, affordable housing, with an increased emphasis in recent years on people who are homeless. Also builds ramps and facilitates home modifications.

Attendant referral. Recruits, interviews, checks references, prepares and updates a list of attendants, helps mediate and resolve any problems that arise with attendants, helps with attendant management and training, and helps people to figure out the best way to use their attendant service hours.

Independent living skills training. Holds classes and works with individuals to learn specific independent living skills, such as money management and socialization.

Youth services. Hosts workshops on topics selected by disabled teens, provides peer support opportunities, matches disabled teens with adult mentors, and helps teens locate jobs, and assists youth to use other CIL services.

Peer counseling services. Support and active listening between two people who have similar disability backgrounds.

Job development. Helps job seekers with goal identification, interview skills, resume writing, job search techniques, and actual referral and follow up. Also conducts disability awareness workshops with employers and affirmative action officers within companies.

Benefits counseling. Helps people to get all the benefits they are entitled to, and helps people who have trouble with these benefits.

Blind services. Provides peer counseling, reader referrals, talking book certification, and skills training to "blind and low vision clients."

Deaf services. Makes all CIL services accessible to deaf and hearing impaired individuals and referrals.

Independent living skills training (mental disabilities). Program specifically designed for people with mental disabilities, previously based on a classroom model and then changed to individual one-to-one training in independent living skills.

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housing, employment, peer support, and advocacy (which includes benefits counseling and client assistance).

As listed in Chart 1, CIL continues to be actively involved in both individual advocacy and systemic advocacy, though many of the staff members report 80-99% of their time is now spent on supportive services. Critical systemic advocacy issues at the time of the visit as expressed by staff members at the center are included in Chart 2, and are shared here because of their continuing importance in the disability field.

CHART 2
Systemic Advocacy Issues (1989)

Passage of the Americans with Disabilities Act. This was "on the top of the list across the country." As one staff member explained, "ADA is exciting. People who think that ADA will be devastating to their business will see that they're wrong. The 1990s will open up a lot of new changes."

Personal assistance services. Personal care could be included in a national health insurance plan, but other critical issues such as the pay scales for workers also must be addressed.

Employment. This will continue as "a very important issue for people with disabilities...in the 90s into the 20th century. Two thirds of the disabled capable of working are unemployed. One third of those employed are on the low end of the pay scale. Benefits are a work disincentive. They lose their medical and medicare and companies will not provide the type of insurance they need."

Health insurance. "We need a national health plan that would include people with disabilities. A number of insurance companies will not include you if you have an existing health problem. Insurance companies say if you go to work, you're not disabled."

Telephone relay system for deaf. Only a few states such as California have it, and it's needed nationwide.

Who are the Staff Members at CIL?

Some of the key CIL staff members hold a deep personal commitment to what the organization has stood for in the lives of disabled people in Berkeley, the United States and around the world partially because their personal experiences with disability and the agency have touched their own lives. The following are a few stories about their lives in relationship to the Center for Independent Living.

Katie Clemons[4]

I've been working at CIL about nine months this particular round (as coordinator of attendant referral). In 1974, I was living in Oakland and working full-time on politics. I ended up having my wheelchair broken all the time. In those days, things are better now, if you had wheelchair problems...you'd be down for a month. Finally, some guy at this place that I bought it...said call CIL...They came, got me, wheeled me in, jacked up the chair, and fixed it like in an hour. I was so impressed.

Anyway, it was a very small staff...they had a little Volkswagen van that was the only transportation in those days...they had advocacy...attendant referral. I had always worked with my friends who had been involved in the same things I was in and they had taken care of me. Then (I met) all these people with attendants. And it's like "I Want Attendants." So first I started volunteering and then I wanted a job so I could get attendant money.

I went to the director, who was Ed Roberts at the time, and said "Could I work for you?" In those days it was very loose, and he said, "What would you

[4]All names used in the report are actual names except for those marked by an asterisk (*), indicating people who could not easily be reached for permission to use their names.

like to do?" I said, "The only thing I've ever done is politics." He said, "Great, you can work with Sam*." Mostly up until the time I moved to Mexico in 1981, I worked in what was called the community affairs department...We did transportation organizing...health and welfare benefit organizing...We went to city, regional, state, (and) federal hearings and gave testimony.

During those early years, Katie was part of the coalition that participated in the sit-in for the Rehabilitation Act. As she shared, "It has transformed a lot of our lives, a very personal experience that was the most important thing many of us have done or may ever do in our lives."

Gerald Baptiste

I lost my sight at 29...I went to sleep one night and woke up one morning. I thought I was just tired because I was working 16 hour days. I was at a job at the county and...waiting tables and taking legal accounting and doing jam sessions...I found out (the loss of vision) was hereditary; nine out of ten times it doesn't come back. I continued to work and after fifteen years...I had two discs (from my back) removed. Six months to a year after the operation, I decided to put in (file a disability claim) for my back, not my eyes.

While I was recuperating I (decided to) give up six months to the movement. I started in blind services eleven years ago...I had not totally accepted my disability. I would take the glasses off even though it hurt. I didn't want to explain...Not only did I come to like what I was doing, but I liked what the

Center was doing...I got the nerve to take (the glasses) off because I realized that this is...part of me. And the person who has the problem is the person over there wondering...I don't have a problem. I know what it is.

As with all organizations, some of the "old guard," such as Judy Heumann and Ed Roberts, have moved on from CIL and are now involved in disability work internationally through the World Institute on Disability (WID). Some of the newer people may not have been part of the same struggles and may have been drawn to the movement partially as a result of its success in reaching and influencing the mainstream rehabilitation community. Marcia Ortiz, who is a job coordinator at CIL, is an example of a person whose training and roots partially stem from her experiences in rehabilitation services.

Marcia Ortiz

I was teaching in a developmental model...I thought this is not real; this is not going to help their lives...I went through this seminar with Marc Gold. That really changed my outlook and the way I saw myself, saw what I need(ed) to be doing to help...the people I was working with potentially have a quality of life that was comparable to my own...I started looking around the community in terms of what resources they had available and how else they could use those resources...I saw the people I was working with in a totally new light. And I really enjoyed seeing them in a new way because it...rejuvenated my energy and my focus and it made me have more ideas and hope.

This organization today is a combination of the "new" and "old," and this history and the dilemmas it reflects will be touched on briefly in discussing how the organization has changed with the times.

What are Independence and Independent Living?

Independence and independent living are defined in many different ways. At the Center for Independent Living, the people I interviewed shared the following meanings for the words that form the foundation of CIL's efforts to promote full community participation. To people here independence and independent living mean:

- different things to different people
- you know what you need and if you can't do it all yourself, you know that you have to get some help and you can get it
- learning how to do what you need to survive
- empowerment...to make decisions for themselves and to have the types of policies that allow it
- being able to live as well as you can as well as you are able to
- it varies with every individual...mainly the freedom to make your own decisions about things
- all disabled people have the right to live the kinds of lives they want...the rights to participate in community and politics...rights like anyone else

Independent living is based on the recognition of a choice of lifestyles and the removal of barriers that impede such choices. As one staff member explained, "Some people will never be able to live totally on their own. A lot of people don't want to live totally by themselves. It's their choice." And another said, "You might need an

attendant or you might need a therapist; in some ways, we all have some barrier to living as independently as we would want to. But just the ability to make your own decisions and your own choices...that's what living independently is." And as David Lewis, CIL community relations coordinator, concluded,

> For people who have experienced independent living, I don't think they would ever have anyone take control of their life again...We have a right for equality, a right to participate in any part of society that anyone else does. I hate to be treated special, the back of the bus syndrome. It still happens.

The Berkeley Community: An Accepting Place

Berkeley is a community of about 80,000 to 90,000 year-round residents. Partially because of its reputation as an accepting community, over 15% of the population has a disability of one kind or another. Several people at CIL believe the nature of the Berkeley community itself was instrumental in the start of the independent living movement. As David Lewis shared about the community he has chosen to call home,

> This is a very open, accepting community. I don't know if the idea of independent living would have taken off the same way in another place. The Bay area is a very special community. In other areas, people fend more for themselves. With the earthquake, there was little looting. It sums up the whole Bay area. People are into community and living. If you live here two or three years, you understand. They really deal with people on face value. People are open. They deal with you on a one-to-one basis, not as disabled, gay or black.

> I've been here ten years. Every time I leave I feel different. I don't feel that I stand out here...Little kids are exposed to people from all over the world. The exposure is there. You can't avoid disabled people.

At the same time, the influence between the independent living center and Berkeley are in many ways reciprocal and mutually build on each other. As Katie described,

> I think Berkeley is the most disabled-friendly community in the United States. There's no question about it. They have a disabled commission and open up all issues. It's very, very accessible...that has a great deal to do with the fact that CIL was very community oriented in terms of advocacy on the (city) codes for...restaurants and that kind of stuff.

Looking today at Berkeley, one sees a city that has responded to include its disabled citizens and to assure that their daily needs are part of the city's daily business. As one example that other communities may want to investigate,

> One thing that is really, really, invaluable, the City of Berkeley has emergency attendant services. They also have emergency wheelchair repair and emergency transportation if you break down or something...I think they have emergency interpreters too. It's called "Last Call Emergency Services." It is funded by the city, and it is absolutely a godsend because there are times when an attendant doesn't show up. (In) Berkeley, you just call this number and they have attendants on call, who are on beepers. The city pays them $10 for a call and the client pays them $7. It can mean the difference between getting out of bed or getting your catheter changed or whatever, but I think it's just tremendous.

Of course, Berkeley still has its own problems, but it's become a place where the government and disabled people have started to join together to develop a quality community life.

LESSONS FOR THE DEVELOPMENTAL DISABILITY FIELD

The Center for Independent Living was selected for study since many "good" practices identified in the Center on Human Policy's national study of developmental disability service organizations appear similar to those in the independent living movement. In particular, the visit was structured to explore the meaning of independent living for people with developmental disabilities as perceived by people involved with the independent living center.

This section highlights six major areas of concern to people interested in the developmental disability field, presents the views of CIL, and draw some implications in relationship to people with developmental disabilities. The areas addressed include: choices and decision making, peer support, working with attendants, disability awareness, advocacy and services, and transition and independent living.

Choices and Decision Making

The issue of choices and decision making is a critical one in the developmental disability field, often complicated by the perceived inability of people to express choices, by legal issues of competency, and by ethical issues related to safeguarding. While staff members at CIL seldom have experiences with the complex forms of these issues, the organization holds a strong value stance about choices and decision making that is often lacking in the parent-, provider-, and professional-dominated discussions in the field of

developmental disabilities. Views of CIL staff members made prominent in this section include the importance of individual preferences, learning through mistakes, the lack of opportunities for disabled people to make choices, and ways of decision making.

Individual Preferences

One important value underpinning this organization is its strong recognition that each individual is unique, that personal preferences extend to the smallest aspect of a routine, and that people generally prefer to do things their own way and not have those choices imposed by others. Katie explained:

> The thing that we, all of us, feel strongly about is that...you have twenty people with twenty different ways of doing things. Everybody has their own way they liked to be helped out of their shirt, or put on the toilet, or whatever, and they don't want someone coming in with preconceived notions.

While a respect for individual preferences creates a strong foundation for decision making, it does not address the nature of any relationship when two or more people wish to do things their own ways. It does, however, stress the role of the disabled person as employer and the primary decision maker on how things are to be done. As in all relationships, though, underneath is a process of negotiation and exchange that cannot so neatly be boxed and labelled into the roles of employer and employee.

This strong belief in individual preferences is also reflected in the strategies of day-to-day living discussed in support groups and in individual peer counseling sessions.

One of the main roles of the staff is to present options, so people can use the information to make decisions that suit them. As Lisa Simmons*, who works in "blind services," described,

> It's funny because each system works for a different person, and my system of organizing things might not work for you and vice versa...We really try to get the individual to see what works for them...I feel it is my responsibility to give people the options, then it is up to them to decide how to do it.

While Lisa will share her experiences on what has been helpful in her own life and the lives of other people, she recognizes that many solutions are possible for any given problem. She continued by giving specific examples of strategies a person with a visual impairment might use in organizing their wardrobe.

> There are actual little plates that you can attach to your clothes. It's very cumbersome so that's really not recommended. Then there's tying knots, and that can also be very difficult, tying (a) different number of knots for each color...Another way to do it is by color. Put one side of the closet with purple, one side with blue and in the middle maybe the neutrals. And some other people organize by outfit. I don't normally wear the same blouse and skirt together all the time, so it would be difficult to organize by outfit. One person I know bought only one color.

In addition to presenting options and sharing personal experiences, staff members can also help disabled people gain confidence in themselves and their capacity to make choices. This is viewed as a critical role that CIL plays because the tendency on the

part of people and agencies is to try to take care of disabled people. In doing so, a person's own strength, self-esteem and sense of security can be undermined. As one staff member explained about CIL,

> I grew up with a mother that was disabled and been part of the disabled community here for sometime. Coming into CIL is putting out information and putting out choices and leaving it up to them rather than doing it for them. When dealing with disabled people, people want to take care of them. It can undermine people's confidence and sense of security...We supply transportation, telephones...don't undermine them.

In the view of CIL, supporting choices is intimately tied to a respect for each individual, an individual's respect for her or himself, and the person's right to a life of dignity.

Making Mistakes

One of the ways that human beings learn is by making their own mistakes, observing what occurs, and deciding what it means in their lives. While parents often wish their children would accept the wisdom of their experiences, this scenario of learning from and through one's own efforts repeats itself generation after generation. It is often considered to be part of the growing up process of moving toward adulthood.

Disabled children, however, often do not have these opportunities because their lives may be regimented and controlled by many good-intentioned people who feel they know what is best for them. Sandra Stone, who works with disabled youth, compared this experience with that of being a parent:

> The thing we have to remember is...they're going to make mistakes. And sometimes watching kids make mistakes is really hard. Having had my own,

> you've got to cringe and let them do it...that's how they're going to learn...and pick up the pieces. So I think that kids with disabilities don't get that chance because their lives are so organized and supervised, and everybody knows what they need. And they don't get a chance to kind (of) make choices.

What Sandra describes is a relationship based on hard work and caring, of being there with people through the mistakes and into the continuation of their life process. As Sandra explained, she would intervene if she could prevent a situation that was totally destructive. However, she starts from the base that we all make mistakes, whether we are disabled or non-disabled. In contrast, when disabled people make even minor mistakes, service providers and others may curtail their future opportunities for choices. Being told they are not ready when they make a common human mistake, the world of the disabled person can become more restricted. Also, through the loss of external support and caring, their own confidence and willingness to take risks may be undermined.

Lack of Opportunities

Disabled people, even as adults, may have few opportunities to make choices. For example, people who have lived in institutions can reach adulthood without having any opportunities to make even simple, day-to-day choices that we all take for granted. As Phil Chavez, who has been involved for fourteen years with the independent living movement, shared:

> (In) a lot of institutions, you don't get a choice what you eat (or) what you wear...(Even with) basic things like food and clothing, you have no choice. You wear what they give you and you eat what they put in front of you...The

> people...that come from institutions...have been the most difficult people to work with in terms of teaching independence because what teaching independence is all about is that freedom to make your own choices...That concept of making your own choices is really alien to them and not something they ever understood.

Sometimes one's disability label may lead to the curtailing of opportunities for choice. As another CIL member explained, developmentally disabled[5] people who are "mainstreamed in group homes" still may be restricted in making even simple day-to-day decisions. This appears to be based partially on a view of the people as lacking the capacity to make choices and also on the tendency of providers to take on the decision making role for these individuals.

> Particularly the developmentally disabled don't get a chance to make choices. People don't even make simple choices about what they're going to wear...someone just comes along and pulls the clothes out of the closet. So if you can't even make those kinds of choices, how are you going to make other choices in life?

The following are two stories about some "weird" expectations of providers, as shared with me by one of the CIL staff members. The stories center around the issues of diet and relationships, two common areas of contention between disabled people and providers. In each of these stories, the position of the providers appeared to be that their actions were taken on behalf of or in the best interest of the disabled person. The CIL staff member, however, saw these events in another light as she recounted:

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[5]Common terminology used during this visit, though the meaning appeared to vary with different staff members.

> Susan was an older woman, and she was just very warm...So we hit it off right away...She used to come to school with these strange (carrot) sandwiches...and really weird dietary kinds of things...We used to make hamburgers, and she used to bring lunch. Her care provider was some kind of strict...vegetarian...Susan wanted this hamburger and her care provider would not let her have the hamburger. And the care provider was saying...she will get real excited when she gets home and it's not good for her mucous membranes...and these health kinds of things.
>
> This is real weird, too. Sam couldn't go home and visit his mother because the careprovider said when he went home he came back really upset. Therefore, she (the careprovider) said he wasn't going to visit his mother.

While many providers feel that they must make such judgments about health and relationships for disabled people, this staff member found it incomprehensible that this was within someone's right to do so. How could a provider assume the right to disrupt a relationship in this way or to control an adult from making a decision about what they would eat? These were not even matters of life and death, but of everyday preferences in living.

Ways of Making Decisions

As Adina Frieden of CIL's independent living skills program explained, "When anyone is living their life and being an adult, we set goals unconsciously all the time. People with disabilities are not often challenged enough, given enough chances to make decisions." Part of the work of CIL is offer disabled people new opportunities to challenge them to grow and develop.

People have many different ways of making decisions. Part of the process of helping people to become independent is to figure out with them the ways they already make decisions. For example, as described in a goal planning book for disabled youth (Summer, 1984), prepared under CIL auspices, people can approach decisions and choices in some of the following ways:

- Letting the environment decide.
- Letting other people make the decision.
- Acting without reflection.
- Postponing thought and action.
- Deciding against someone or something.
- Going along with the crowd.
- Basing decisions on what feels right.
- Doing what pleases others or makes them happy.
- Weighing the facts.
- Becoming overwhelmed and indecisive.

Summer advises that once a person determines the ways she or he makes decisions, the next step is to "take control of your life." According to Summer, this is accomplished by "weighing the facts," which is an approach also supported by service agencies involved in the lives of disabled people.

Whenever agencies and workers become involved with disabled people, the tendency is to help disabled people decide in the right way by the right process. The right way usually means the acceptance of "mainstream" values of the dominant culture often to a standard not achieved by most members of the society. In Western societies,

this right process tends to be based on the valuing of a rational approach. While CIL recognizes the diversity in decision making approaches and lifestyle values, they accept this rational, fact-weighing approach as the best decision-making process for disabled people to aspire to.

Peer Support

Peer support, as a concept, tends to be poorly understood in the field of developmental disability, partially because of the strong discrimination and stereotypes that people with these labels face. Because developmentally disabled people are often viewed as "not like us" by other people, the language of "peer" has been used to enforce segregation and exclude these individuals from activities with nondisabled people of the same age. As one CIL staff member explained, this lack of valuing of developmentally disabled people is pervasive and extends to within the disability community.

> I see (people with) developmental disabilities being...on the bottom rung (of a ladder)...because they don't have anyone to advocate for them, and they don't really advocate for themselves much. I really think it's a bad thing.

This is starting to change as self-advocacy groups continue to proliferate across the country and a national organization is being formed. However, on a day-to-day basis and in political life, developmentally disabled people themselves are not part of the mainstream of the disability community.

Peer support--support and exchange by people with "like disabilities"--can take many forms, including peer support groups, classes, and individual peer counseling sessions. The concept is similar to that shared by most self-help groups, such as groups in the women's movement, Alcoholics Anonymous, and fathers' rights. In some ways,

the self-advocacy movement (of people with developmental disabilities) has similar self-help roots, though the latter has become more politicized on the national scene.

One new staff member, there only five days, explained the benefit of peer support:

> When I first got here, I applied for SSI...I was becoming increasingly frustrated. It should be a prerequisite to work with clients to go through this. It's monstrous. On top of everything else, you end up feeling bad. Here you get treated as a human being. You get treated with respect...Other people don't understand or they don't care. In that respect, we do a lot.

Peer counseling is one method or strategy for peer support. As described in Chart 1 (see page 6), peer counseling is now a fundable category under the California Department of Rehabilitation, and is defined as "basically support and active listening between two people with similar (disability) backgrounds." As one staff member explained, "the difference between peer counseling and strict counseling is that there's a lot more sharing and personal exchange."

CIL was involved in earlier research studies on peer counseling and what it might mean in the lives of people with disabilities. As one person who had worked as a peer counselor fourteen years ago said, CIL proved that peer counseling was a really viable option and that it was cost-effective for people to live independently.

As outside organizations have incorporated new practices promoted by the independent living movement, the methods for peer support have changed going full circle from individual to group and finally back to working with individuals. As Phil Chavez talks about his observations through the years:

> Hospitals and rehabilitation centers in general have improved to the point that we're seeing a lot fewer and fewer strictly spinal cord injury clients...They've come around to our way of thinking...They realize you just don't work with the physical body, ...you have to deal with all the psychosocial issues of the disabled...In a sense we've come full circle back where we are working (again) with individuals who slip through the cracks.

Support groups, whether held formally or as part of other activities, give people an opportunity to talk about issues they might otherwise not have a chance to express. Peer support gives people a chance to find out that they are not alone and to benefit from the experiences of people who have faced or are facing similar issues. As Sandra Stone talked about one of the camping trips with the kids, she said,

> People need to talk about their fears of abandonment, need to check out how they are accommodating to their disability....(They talk about) girlfriends, boyfriends, having children, feeling parents don't think they are perfect, sexuality, (and) equipment...If you have lemons, make lemonade; if a wheelchair, pop wheelies...I'm quiet, just let them say their stuff. We like each other as people... I'm legally blind. I know what it's like to be disabled. I was mainstreamed with no peer support, either sink or swim.

Peer support also provides opportunities for friendships and a chance to say things that others, including parents, might be concerned about. Disabled adolescents, like their non-disabled peers, are forming their own views of the world and need opportunities to discuss their emerging issues with peers away from the eyes of overseers. As Sandra continued:

> The peer stuff is very important...Our program is good to meet people, make friendships. In support groups, people can talk about families and the struggles people are going through in their daily lives...Some of the families would be aghast at what we would say.

Assisting people to make friendships and support connections outside the disability community, however, does not seem to be part of what CIL sees as a primary role.

Working with Attendants

People with developmental disabilities are now being supported, in some places in the country, to hire, supervise and manage their own attendants, workers who can provide assistance with a range of daily living and personal assistance needs (see Chapter 9). As Katie explained about the change in people whom they have supported through the years, "It's really a testament to the movement because people are coming to us for attendants who...ten years ago clearly would have been in nursing homes."

Based on discussions with staff members during my visits, developmentally disabled people involved with CIL appeared to have mild disabilities and lived with families, in institutions, or group homes. Most participated in the independent living skills training program and were not involved in the agency's other services, such as attendant referral. As one staff member talked about the future role of the independent living center with developmentally disabled people,

> In the '90s, maybe we'll be working with more developmentally disabled people now that they live in group homes. If they start to mainstream, we'll need to provide support services.

Working with attendants is a new area of interest for most agencies in the field of developmental disabilities. This independent living center, together with others in the country and Canada, has a long history of involvement in attendant services and are usually knowledgeable about the strengths, problems and issues in the design of such a system. A few of these areas are discussed here, as shared by Katie, who also has an extensive personal history in the use of a personal care attendant system.

Recruiting, Interviewing and Problem Solving

The recruiting, interviewing and reference checking of attendants is done by the attendant referral department at CIL, together with the huge outreach that is necessary for recruitment. The department also takes the job orders, works with people to some extent on attendant management, and problem solves issues between attendants and the people they work for.

During their most recent outreach project, CIL placed notices on all the community college bulletin boards and contacted employment offices. They received the most response from a radio ad on a soul station.

Katie described why it was important to have disabled people involved in the interviewing process for personal care attendants.

> When...somebody...comes out of a home health class and...refer(s) to people as patients, ...we can say, they are people just like me. (They) need to be gotten out of bed in the morning, but then they go about their regular day. Patient applies when you are in the hospital.

Each attendant is required to sign a code of ethics that they have read. This includes a statement that they can't abandon a client or breach confidentiality. Problems do, at times, occur including attendants "ripping off" people, and people who continually ask attendants to work overtime or who change the schedule all the time. CIL does what it can to help resolve these issues, though they have limited resources to do so on an extensive basis.

Training of Personal Care Attendants

As described earlier, each person has their unique ways of doing things, and each attendant must be trained by each individual to work cooperatively with him or her. Because of the importance of this individual orientation, Katie said, "There's a very strong bias in terms of people being able to train their own attendants." At the same time, Katie explained that a training program might also be useful, if certain conditions were met, including the attendant being paid to attend it. In describing the content of such a training and orientation program, she suggested:

> I think a lot of the stuff they would need to learn is each person is an individual and you need to work cooperatively with the person. And if you think you're coming in to take over their lives, you're not...And here are some different types of transfers (i.e., ways of lifting and moving a person), but just be willing to learn whatever it is your particular person wants to teach you.

Wages, Benefits and Turnover

Like support staff in the field of developmental disabilities, attendants tend to be poorly paid workers, who may not even have the basic benefits that workers in other fields take for granted. The turnover in these positions is high and it is hard for people

who are good at this job to be able to financially afford to do it for an extended time. Katie explained,

> The county only pays $4.25 and that's horrible...because the cost of living is so high out here...A lot of our attendants have recently been the kind of people who really wanted to keep doing it, but it is very hard because they have no benefits. I think that's what makes people move on, and that's what makes the turnover so high.

Partially because of the low wages and benefits, disabled people will compromise what they need in order to come up with a schedule that is reasonable for the worker. While compromise is an important part of any relationship, these are often compromises borne of necessity and based on a starting point of inequality. As one staff member explained,

> We'll talk with them about what is the best way to divide up the hours...It's a delicate balance...even being able to find somebody at that rate. (If) they need...somebody for two or three hours in the morning and an hour at night, ...we might just say two hours in the morning and two at night. Some people just really compromise what they need in order to get an attendant.

Modes of Personal Assistance

Personal assistance can be set up in a variety of different ways. When the generic personal attendant system is made available to people with developmental disabilities, agencies typically are responsible for hiring, firing and managing the workers. In contrast, the preferred form or mode by many people involved in the independent

living movement tends to be called the "independent provider mode" in California. Katie explained why this mode, where people find and hire their own attendants, has been viewed as critical.

> Where the welfare department hires the person...the attendant does get benefits, but the clients get a lot less service because the county spends the money on the benefits...The people do not get a choice of workers. Now for some people, that's not a problem...(they are) glad to have a guaranteed person coming out.
>
> Traditionally, in this state...people we represent...have been opposed to anything resembling home health where you do not get to choose your own attendant and train and so on....Perhaps we have had a more hard line stance in holding the line against home health agencies getting into the picture at all because we feel strongly that they're making money off this situation and there's not enough to go around anyway. Up until the recent past, we haven't had that many clients who weren't capable of training their own attendants.

Even when people are capable of managing their attendants, they may prefer that an organization perform some of the management functions for them. Other people may not be able to do the management, but would prefer a relative or friend to perform these functions instead of an agency. Increasingly, it is becoming important for personal assistance to be set up so different ways are possible, not based on disability, but on preference. This could include direct management by the disabled person or someone selected by them; management by an agency; or shared functions between an agency and the person and/or their representative.

Disability Awareness

Those of us who were involved in the '70s in the work around the implementation of Section 504 of the Rehabilitation Act, vividly recall the massive disability awareness efforts of the time, particularly with employers and schools. These efforts often included trainings or programs that helped employers and students learn about the experiences of disabled people and confront their own stereotypes and myths. These efforts are continued today at CIL. As one staff member described these efforts,

> (Disability awareness) is basically providing training for people who are not familiar with working or being with disabled people...It could be going down to the Oakland Coliseum, ...to a kindergarten or first grade class...I went to county nursing homes and taught their staff...They have some of the same stereotypes and misconceptions that a first grader or kindergartner would have.

Through youth programs, CIL continues to touch the lives of non-disabled students at a time when their views of the world and people are still being shaped. The programs are oriented toward students becoming aware of and accepting of differences between people, while at the same time, conveying a message of similarity among all people.

> Disability awareness (helps)...(non-disabled) youth...to be more receptive of the kids with the differences; ...it's good for them to be more aware of differences in our society, and I think, more tolerant of people.

In particular with the increased emphasis on "mainstreaming," staff members at CIL believe it is imperative that disability awareness and sensitivity training be conducted where disabled students will be mainstreamed. As David Lewis elaborated,

> Mainstreaming works...(but) it's not easy on the people being mainstreamed. They need to make a commitment. It's difficult at times to be that person. My secretary said it's hard to be the only person who is not white. It's hard to be the only anything, but you have to do it.

As these staff members explained, little attention has been given to the hidden leaders of the mainstreaming movement: the individual students who through personal courage made it possible for the next generation, they hope, to have an easier experience. Through student leadership, visible changes have occurred, both at school and at work. As one staff member said,

> The longer the ILC has been in existence, the more and more people have been mainstreamed. We are starting to reap the benefits of 504...lots of highly trained people ready to work.

Advocacy and Services

One of the most critical issues facing this organization is the tension between its two major functions of advocacy and services. Mentioned also in the agency's recently developed five year plan, this tension between advocacy and services was on the minds of the people at CIL at the time of my visit.

The associate and executive director of CIL are very actively involved in national advocacy issues, particularly through their leading roles in the national organization of the independent living centers. However, on the systemic advocacy level, most staff members believe that "advocacy is much diminished," partially because the movement "was in its heyday in the '70s and '80s."

Many of the staff members feel that "advocacy is done most often within a service context." By this, people mean that they will fight, when necessary, to have the individual obtain the benefits or services that they need. This is partially possible because laws are now in place for people to file individual lawsuits.

CIL also is placing a greater emphasis on having "staff think about teaching persons to advocate for themselves." Staff members are proud that CIL has an advocacy perspective, holding the perspective that "when it's necessary, we will go down to the county board of supervisors, and we will get on coalitions, whatever it takes."

What is viewed as most critical, though, is service to clients. As the associate director explained, "The field is so sophisticated now, (funders are) looking more to see that we'll deliver...quality services...We have some (independent living) agencies who only did advocacy (and) couldn't leverage money with foundations...We must maintain both services and advocacy." As another staff member described this tension,

> The organization's gone through a lot of changes...but it had to do services. People who donate money don't like to hear the word advocacy. It is hard because it is a fine line. You have to tone down your act. This organization has been involved in the disabled movement...had to be advocates. This organization is very influential in all major legislation in this country. It's always been an advocate and a service coordinator.

The nature of the organization's systemic advocacy has changed with the times and now more emphasis is placed on negotiation as the process for achieving change. Previously, more visible activism would have been the primary strategy.

In the old days, we would have been carrying out wild actions, but it would have been necessary because it was not an accepted and understood thing, that discrimination against the disabled was a really bad thing, that it was a minority group.

We've changed the way we advocate. We don't need to go to the streets the way we used to. Now we sit down and convince people. The role of advocacy has changed and we need to do things in different ways. Our reputation from the 1970s helps; people know if we believe in something, we're not going to give up.

Transition and Independent Living

Developmental disabled people are involved with CIL primarily through a independent living skills training program, located in a house on the same street as the main center, one of four off-site offices. As Phil and Adina explained, "We aren't like the rest of CIL, more programmatic" and "we're the only structured program."

One of the major issues faced by the organization today is creating a vision and deciding upon ways of supporting people who previously were not involved with the independent living centers. In some ways, this tension is being played out around transition programs and their place, if any, in an independent living center. The following are the two major positions on this issue followed by a discussion about what the current impasse seems to suggest.

The Experiences of Staff at CIL

The staff members who are most involved with developmentally disabled people on a service basis are deeply concerned that independent living will not become a reality unless these individuals obtain greater support than they currently have. These staff

members have concluded that the solution would be to create a transitional program for these individuals whom are viewed as needing more services than other CIL clients. As Phil and Adina explained their views,

> I thought it'd be great to have a transitional program for people who can't make the leap from family to their own place. Unfortunately, some folks...are opposed to any residential component. They think HUD (Housing and Urban Development) buildings are institutions.
>
> It's important to have a transitional program so people don't need to leap over a chasm. For people who are mentally retarded, it is almost impossible to do it. The old guard won't have anything to do with transitional programs.

The "old guard" is deeply committed to a vision of people living fully in community, and seem to be concerned about what it would mean to establish residential programs for any group of disabled people. This view gets labelled as philosophy because the translation into what it means on a day-to-day basis has not occurred, and developmentally disabled people are left without the support to live in their own place.

What We Have Learned and What the Impasse May Represent

People at CIL are just becoming familiar with information on the creation and efforts toward a new vision of life in the community for people with multiple (mental and physical) disabilities. This vision, being transformed into reality throughout this country (see Part I of this book), supports the right of all people to live in their own homes with the availability of supports.

With this information, the question can be transformed from "Do we need a transitional program?" to "How can we support people to lead the same range of lifestyles as anyone else?" Such a reformulation allows both for the vision of the "old guard" and the discussion about what role CIL can and should play in supporting this vision on a day-to-day basis in the lives of individuals.

In the field of developmental disabilities, people have learned about the problems with transition, readiness, and isolation on the backs of disabled people. This discussion now offers the opportunity to re-examine the role of the independent living center in a society that has been changed by its efforts so that "mainstreaming" today applies in ways even "the old guard" might not have imagined.

As Ted*, who participates in the independent living skills program said,

> I hope it works out to my benefit...I just like to see myself better in a lot of things and try to make myself a lot better...I'll know if it works, if it feels good inside...People treat me the same way they do everybody else. I want it that way.

Ted, and others considered more severely disabled, have a right to a home with the personal assistance and other supports they need. People at CIL, in alliance with others, should settle for nothing less.

CONCLUSION

The Center for Independent Living at Berkeley, one of the sites of the creation of one of the most important social movements of the past decades, stands today as the bearer of the great responsibility that comes with that honor. As Gerald Baptiste so astutely explained, "Organizations must grow with the times."

However, as the climate in this country has resulted in decimated funding for social efforts, this organization has increasingly relied on financing which it believes restricts its efforts to advocate in the manner to which they have become accustomed. While the organization may say the times demand new methods for change, the picture of disabled people crawling up the steps of the Capitol in Washington, D.C. for passage of the Americans with Disabilities Act (ADA) touched the hearts of many people nationwide in a way negotiation will not and cannot.

The movement has reached a new stage, one where a more inclusive vision of full community life must include a broader base of people. Because of its efforts, CIL has led the way. In the future, it can continue such a leadership role by reaffirming its role and place in the movement, by creating new stories of the 90s that inspire the best in people, by distinguishing the service roles of an independent living center, and by developing a stronger, broader community base for the work and challenges that lie ahead.

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